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ABSTRACT

Planning for infant intervention programs is the focus of the booklet. The approach rests on key principles, including family support, interagency cooperation, and individualization of early intervention services. Questions are raised for consideration in six topic areas: (1) planning (structure of planning process); (2) funding (legislative authority, long range plans, types of competitive or entitlement approach); (3) programming (location of services, individualized programming options, specific policy guidelines regarding service delivery models); (4) personnel (staffing patterns, certification, licensing, preservice and inservice training); (5) eligibility (use of noncategorical or categorical guidelines, responsibility for locating and identifying eligible children and families); and monitoring and evaluation (responsibility for planning and implementing the monitoring system, quality issues of service delivery as well as compliance with regulations). (CL)

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PLANNING PROGRAMS FOR INFANTS

by

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Much of the development work for this monograph was accomplished in a series of committee meetings by the contributing authors, most of whom are INTERACT board members. INTERACT is a national organization for early intervention advocates and professionals who are concerned about assured, quality, comprehensive services for infants with special needs and their families. Special thanks must go to Nancy Obley-Kilborn for meeting with us and sharing her thoughts from a state perspective; to Joy Hicks for her contributions in the area of multicultural issues; and to Nina Carran for her support and assistance throughout the planning and production of this paper. We wish to acknowledge the financial assistance of the Consortium of State Coordinators of Early Childhood Special Education, administered by the Iowa State Department of Education.

INTRODUCTION AND PHILOSOPHY

Early childhood professionals who are developing a state plan for comprehensive early intervention services are confronted with a variety of complex issues. To help state planners examine these issues, this paper poses questions central to the planning of services for children with special needs birth to age three and their families. We have neither intended nor attempted to answer these questions; to have done so presumes that all states have the same resources and experiences, and that a single approach is "correct" for all state programs.

No two states are alike in the way they have served, or will serve, infants. And, this diversity was an ever present, underlying consideration throughout the preparation of this document.

We acknowledge that no single system of service delivery is appropriate to all agencies, or to all children and families. And, we recognize that programs with a wide variety of theoretical bases and service models can demonstrate their effectiveness. However, for this paper, we have chosen a particular philosophical bias that asserts the uniquely dependent nature of the population in question and acknowledges the family, rather than any program of early intervention, as having the greatest influence on the children's development and future outcomes.

As young children with special needs move through the infant and toddler period, they and their families require the services of specialists from a variety of fields. These professionals, with the parents, will need to be involved in planning and choosing necessary services from among an array of options which might include screening, diagnostic evaluation and assessment, well-baby care, medical management, developmental programming, day care, respite care, physical therapy, occupational therapy, language therapy, legal and educational advocacy, housing assistance, and employment counseling.

The number and variety of special services often needed by young children with special needs and their families demonstrates to state planners two important principles which should be kept in mind when developing a comprehensive service delivery system. First, infants and toddlers with special needs and their families cannot be served simply by extending traditional special education services to include this age group. Doing so would leave unmet many of the special service needs listed above. Second, no one agency or discipline can provide all needed services.

All children will not need all services. So, planners will want to design an interagency approach which makes all these

services available or obtainable while allowing the unique needs and resources of children and families to determine individual service plans.

While an interagency approach relieves any single agency of the responsibility for comprehensive service delivery, it does require that planners address the process of coordination of services. Planning also must result in a system in which service providers are trained to work not only as professionals within their own disciplines, but also as team members who acknowledge, respect, and rely on the expertise of their colleagues and of families.

Four Principles

In summary, four philosophical principles provide the rationale for the questions raised in this document:

- Infants and toddlers are unique because of their dependence on their families. This dependence necessitates a family-focused approach to early intervention.

- Responsibility for a child's development rests with the family. Programs must support, not supplant, the family's role.

- No one agency or discipline can meet the diverse and complex needs of very young children with special needs and their families. A coordinated, interagency approach to planning and delivery of services is necessary.

- Very young children with special needs and their families have a wide variety of needs and resources. Therefore, state planners will want to devise a system that allows early intervention services to be individualized.

As state planners use this document, they will find that the above four philosophical considerations emerge repeatedly as planning issues are considered. It is for each state to find its own answers to the questions posed. And, we hope these answers and solutions will result in a comprehensive service system and in optimal development for our very young children with special needs and their families.

PLANNING

With the advent of Public Law 98-199 and the subsequent funding by the federal government of state planning grants for early childhood, state policy makers have a unique opportunity to examine the current status of early intervention and to develop a plan for creating, expanding, or improving these services at the state level. This section of this paper poses questions central to the process of beginning to develop a state plan for early intervention.

The structure for the planning process is, perhaps, the first issue state planners should address. Some states may choose a lead or core agency to be responsible for establishing the planning process and developing and implementing the state plan. Other states may choose to form an interagency council or coalition to share equally state plan responsibilities. Whichever approach is taken, each agency's role must be fully and carefully defined.

Once the structure for the planning process is set, planners should begin identifying and surveying the state and local agencies and programs previously involved in developing or providing early intervention services in the state, as well as advocates and leaders supportive of early intervention. Representatives of racial, ethnic, and cultural groups who will be recipients of the planned services also should be identified. A process that allows this mix of representatives to act as resources or participants in developing the state plan provides encouragement and a sense of ownership and commitment by those involved to the policies and procedures established in the plan.

Legislation is another critical issue to be considered early in the planning process. Current state legislation should be examined, and a decision should be made about whether that legislation is adequate or whether new legislation is warranted. Federal legislation should be examined to determine if proposed state legislation and policies are consistent with federal mandates.

Questions for Consideration:

- How will the planning process for the development of a state plan for early intervention be structured?
  - Will there be, for example, a lead agency in developing and implementing the plan?
  - Or, will state planners form an interagency coalition or council to share this responsibility equally?

-- If a lead or core agency approach is chosen, will a system be developed and formalized to coordinate the multiple agencies which share responsibilities for the planning process? How will this system be devised?

-- If a collaborative structure is chosen, how will it be funded?

o Have there been previous efforts in the state to develop a plan for early intervention at the local, regional, or state level?

-- If so, will you be able to use the products or participants as resources in developing the state plan?

o How will individuals, agencies and organizations be identified and used as resources in developing the state plan?

-- Will state planners facilitate networking and interagency collaboration among these agencies for the purposes of state planning?

-- Will parents, professionals, and community organizations involved with special needs infants and their families be identified and used as resources in developing the state plan?

-- Are there federally funded projects in the state, such as personnel preparation grants, demonstration and outreach projects, National Diffusion Network projects, or field and applied research grants? If so, will they be identified and used as resources as well?

-- Does a state early intervention consortium exist? If so, will it also be used as a resource in developing the state plan?

-- Will state planners explore what other states are doing in early intervention planning at the state level? If so, are there guidelines, recommendations, or other products that can be used as resources?

o Will state planners seek legislation for early intervention services?

-- If so, will the legislation sought be mandatory or permissive?

-- If legislation is sought, will it be associated with legislation for handicapped children from three to five years of age, or with any other age group?

-- If legislation is sought, how will it address or relate to federal legislation pertaining to services for children with special needs?

o Will state planners develop a philosophical statement for early intervention services and programs as part of the state planning effort?

o Will early intervention programs be required to provide appropriate services to children and families from diverse socio-economic, racial, cultural, and ethnic backgrounds?

-- How will the state's philosophy on multi-cultural intervention be developed?

-- Will the decision-making bodies for early intervention include representatives of the state's entire population?

-- Will a person be designated at the state level to provide assistance to programs serving culturally diverse children and families?

-- How will cross-jurisdictional issues in serving Native American populations be addressed if the issues arise?

o How will state planners guarantee that families are made aware of their rights regarding all issues relating to their child's programming and individual service plan such as the right to confidentiality and access to records?

o Will provisions be made to assure that children in early intervention programs are served in the least restrictive, most normalized environment as defined in federal legislation and current best practices in early intervention?

o How will state planners determine which are state and which are local decision-making responsibilities for issues of program structure and implementation such as staffing patterns, caseloads, and amount and kind of services to children?

-- Will the state funding agency or any other body be responsible for facility approval? If so, will such approval be tied to funding?

o How will the state plan structure implementation of its guidelines and recommendations?

-- For example, will pilot programs be funded as models, or will across-the-board implementation be encouraged or required?

o How will existing service programs be incorporated into the system or structure for early intervention developed as part of the state plan?

FUNDING

State planners should consider a variety of options for funding early intervention programs. The availability and quality of early intervention services in the state will be determined to a great extent by the amount of the budget, the funding formula developed, and the system used to allocate and distribute monies to programs.

For the most appropriate allocation of funds, it is critically important that funding sources recognize that the needs of children and families vary greatly depending on the type and severity of disability or delay, the resources and needs of the family, and a host of other variables. State planners must develop flexible funding formulas to allow programs to meet the individual needs of these children and families for services that vary in type, placement, intensity, and duration.

Questions for Consideration:

o How will early intervention be funded?

-- Does your state have, or will it seek, legislative authority for funding early intervention?

-- Will the level of funding be adequate to provide early intervention services for all eligible children in the state, or will programs compete for available funds?

-- If a collaborative structure will be used to develop and implement the state early intervention plan, how will this collaborative effort be funded?

-- Will it be possible that several agencies might collaborate in the state plan, but funding may come from only one?

o Will state funding patterns encourage local and regional programs to develop long range plans for early

intervention in their area?

-- If this is a goal, will programs be provided with multi-year funding or alternative cost-reimbursement systems to encourage this planning?

o Will the funding formula for early intervention programs encourage them to recognize the diversity of child and family needs in areas such as the intensity, type, and duration of services?

-- Will this funding formula include allowances for programs serving children with low-incidence handicaps and/or children who live in sparsely populated areas?

o Will the funding formula provide for family-focused services?

-- Will programs have funds to help families find and use other necessary services?

-- Will state funding procedures allow parents to choose among programs, using a voucher system or other flexible funding mechanisms?

o How will programs receive funds under the state plan?

o Will the process be competitive or will an entitlement approach be taken?

-- How will a funding structure be established which assures that programs receive timely payments from the state?

o Will early intervention programs which are funded by the state be expected to provide other sources of revenue?

o Will there be a cost to families for early intervention services?

-- If so, will programs be permitted or required to bill for third-party payments?

-- Who will pay for families that are not third-party reimbursable?

o Will programs be provided with fiscal guidelines or restrictions for line item expenditures such as administrative supplies, office furniture and equipment, programming supplies, adaptive/therapeutic equipment, children's furniture, consultants, space rental or purchase, indirect costs, and salaries?

o What system will be used to monitor the accounting procedures of funded agencies and programs?

ELIGIBILITY

The establishment of eligibility criteria for early intervention services is one of the most important decisions facing state planners. The number of children and families to be served and the type and cost of services offered will be influenced strongly by the eligibility criteria chosen.

Arriving at a definition of the client population is perhaps the most complex issue in establishing eligibility criteria. In general, three groups of young children benefit from early intervention services: those who are disabled, handicapped, or developmentally delayed; those who are medically or biologically at-risk; and those who are environmentally at-risk.

Disabled, handicapped, or developmentally delayed young children may have congenital disorders, sensory impairments, neurological dysfunctions, or significant delays in one or more of the major areas of functioning (cognitive, language, social-emotional, and gross- and fine-motor development). Medically or biologically at-risk young children include those for whom early health factors are known to be a potential threat to developmental outcomes. The most numerous of these are significantly premature babies and those who are small for their gestational age. Young children who are environmentally at-risk include those for whom postnatal physical or social environments are a potential threat to their developmental outcomes. These children include those who are abused and neglected, those whose parents are mentally ill or developmentally disabled, and those from adverse physical environments.

The other critical issues that state planners will want to address in determining eligibility is whether or not families are to be considered part of the client population. Since many agencies have policies and procedures which preclude them from providing direct services to nonclients, the inclusion of families in the definition of the client population may allow programs to support the family more effectively in its role as the primary influence on the very young child with special needs.

If families are to be included as part of the client population, the term "family" will need to be defined. State planners may want to consider a definition of "family" that moves beyond traditional or legal definitions to encompass primary caretaking adults who play major, long-term roles in the child's daily life.

The definition of the client population will have a profound influence on the direction and shape of the early intervention programs in the state. Casefinding, screening, assessment, and intervention practices also will be determined in response to the complexion of the group to be served.

Questions for Consideration:

- o How will state planners arrive at a definition of who will be eligible for intervention services?

- o Will eligibility guidelines provide for non-categorical services, or will programs be required to serve children in specific diagnostic categories?

- o Will guidelines include families as part of the client population for early intervention?
  - -- If so, will "family" be defined flexibly, including those adults who are significant in the child's daily life?
  - -- Are there state or local agency policies which will be in conflict with considering families as part of the client population?
  - -- If so, how will policies consistent with the inclusion of families be developed?

- o Will the state and local programs share responsibility for locating and identifying eligible children and families?
  - -- If so, how will the responsibilities of each be determined?
  - -- Will certain screening and assessment procedures or instruments be recommended or required to determine eligibility of children and families?

- o Will children from birth to three years of age be included in the state Child Count or in some other form of handicapped or at-risk category?

-- If so, what kinds of data will be collected on children and families?

-- What provisions will be made for assuring the confidentiality of this information?

-- How will this information be used to plan for and provide early intervention services to children and families?

PROGRAMMING

Most professionals who work with young children agree that the greatest rate of learning and development for young children occurs in the early years of life. And, most agree that the family has the greatest influence on the child's developmental outcomes. The importance of early intervention programs and the efficacy of family involvement in these programs has been well documented. The basic question then is: How will infants with special needs be served?

Because they are near the beginning of the developmental continuum, infants are almost totally dependent on their families for their survival and nurturance. They require more daily care, stimulation, and teaching than any community intervention program can provide. Program providers must rely on the family to give the time, the attention, and the investment of emotional and physical energy that are necessary for the very young child's optimal growth and progress.

Parents of infants with special needs are learning to be parents at the same time they are acknowledging and coming to terms with the immediate as well as the long-term implications of their child's disability. Those parents also are learning to manage the intricacies of the service networks established to provide programs for their child. Without counseling, support, and attention to the family's adaptation, therapeutic efforts with an infant or toddler may not have their greatest effect. It is the family, after all, who carries out the child's therapeutic intervention during the course of daily caretaking.

Families, like children, represent the full range of the human condition and require different kinds of intervention services and different styles of service delivery. State planners should recognize this diversity when they are developing early intervention program guidelines. Guidelines should be flexible and allow for a variety of service options which take into account the families' ethnicity, cultural values, past experiences, strengths, supports, needs, coping abilities, and abilities to adapt to and use program services. The type, kind, intensity, duration, and setting of services are program factors

affected by this child and family diversity.

Not all families will need all services. Some families will be able to incorporate their new role demands with minimal intervention and guidance and will be able to offer their children healthy and stimulating environments. Other families will be overwhelmed. These families will barely be able to meet either their own or their child's needs and will require a myriad of social, medical, educational, and financial services.

Planning services for a mildly retarded child in a two-parent, financially and emotionally stable family will be a decidedly different task than planning services for a moderately involved child with cerebral palsy whose mother is single, poor, without transportation, and emotionally at-risk.

Early intervention programs should be encouraged to develop individual service plans based on the child's developmental strengths and needs, as well as on the family's perception of the child's problems and their ideas of how those problems can be resolved. To help programs achieve this goal, state planners can examine service delivery models that focus on child and family needs.

Many early intervention programs choose transdisciplinary service approaches because they are cost effective, time efficient, and comprehensive. The transdisciplinary approach rests on the two fundamental beliefs that children must be viewed holistically within the context of the family and that the family must be involved in all decisions regarding services for their child and themselves. Therefore, all team members and the parents must be involved in making decisions about all major areas of the program including assessment; individual service plan development which designates the amount and kind of service, service setting, transportation decisions, etc; ongoing program planning and update; and evaluation of child and family progress.

In summary, four themes emerge which state planners should consider as they develop programming guidelines for early intervention programs:

- Programs should be encouraged to recognize the diverse needs of the child and the family and to develop flexible programs to meet those needs.
- The needs of the family must be assessed and included in individual service plans.
- Intervention strategies for the family must be as clearly defined and systematically implemented as those for the child.
- Programming for the child must relate to the values and resources of the family.

Questions for Consideration:

- o Where will services to children and families be provided?

- o Will services be available in homes, schools, developmental centers, hospitals, and other settings?
  - -- How will the most appropriate setting be determined for each child and family?
  - -- To what extent will families play a role in choosing the service setting? Will they be given a choice regarding placement?

- o Will the state plan address individualized programming options such as type and intensity of services, length of class session or day, physical environment, and group or individual instruction?

- o Will state planners develop policies which enable families to function as decision makers and problem solvers regarding their child and the services they receive?
  - -- Will programs be required to have an advisory committee which includes parents as members? Will the parents and other committee members have an opportunity to determine relevant program goals and policy?
  - -- Will state guidelines allow programs the flexibility to respond to families' expressed needs?
  - -- Will programs be encouraged to allow parents to choose the extent of their involvement in the program?
  - -- Will programs be encouraged to provide child and family services in a way that addresses contemporary family constellations which differ from the traditional nuclear family?

- o What responsibility or requirements will program staff have for engaging families in early intervention?

- o How specific will state policy guidelines or recommendations be regarding service delivery models?
  - -- Will programs be required to have several professional disciplines involved in assessments?

-- Will programs be given recommendations or requirements regarding the mode of team functioning?

-- Will required or recommended assessment practices include behavioral assessments, parent-child interaction measures, and assessments of adaptive skills as well as traditional standardized assessment instruments?

-- Will state planners address program responsibilities for funding medical evaluation?

-- Will programs be required to conduct periodic evaluations of children and families, such as every six months?

-- Will early intervention programs be provided with guidelines to assist them in identifying families' needs and resources and with a range of service options for meeting these identified needs?

o How specific will requirements for individual service plans be?

-- Will programs be provided with pre-printed forms for individual service plans, or will they be allowed or encouraged to develop their own forms?

-- Will programs be required to demonstrate a clear and logical link between assessments of child and family needs and resources and the individual child and family service plans?

-- Will programs be encouraged or required to provide family service goals as part of the written individual service plan?

-- Will the child and family's individual service plan build on their strengths as well as identify areas of need?

-- Will programs be required to conduct periodic evaluations of child and family progress toward meeting the goals outlined in the individual service plan?

o Will transportation be included as a need or service in the individual service plan?

-- If so, will families, as well as children, be eligible for transportation?

-- If early intervention programs will be encouraged or required to include transportation as part of the individual service plan, how will insurance and other legal issues be addressed?

-- Who will pay for transportation: the state or the individual programs?

-- Will there be a cost to families for transportation, or will all families be eligible for free transportation?

-- If there is a cost to families, will a sliding fee scale system be an available option?

-- Will programs be able to be reimbursed for providing families with transportation options, such as cab fare, bus tokens, etc.?

o Will programs be required to define their curricula -- that is, the planned interaction of children and families with time, staff, and materials?

-- Will programs be required or encouraged to choose curriculum materials that reflect the culture of the children and families being served?

o Will programs be allowed to purchase or loan toys and other materials and equipment for parents' use in the home?

o Will state planners develop a policy and procedure on case management?

-- If so, will primary case management responsibility be placed in the hands of one individual?

-- Will state planners encourage service providers from multiple agencies to document how they are coordinating their case management efforts so that accountability can be assured?

o Will the state plan include a policy on behavior management, corporal punishment, and related issues? Or, will these matters be determined individually by agencies and programs?

o Will the state plan include a policy which encourages programs to examine the language in which services to children and families are provided?

-- Will families have the right to receive services in their primary language, or to have access to a translator?

o Will state planners develop policies and procedures to address health and safety issues for children served in groups, such as child/adult ratios, management of medication, immunizations, and services for medically fragile children?

o Will programs be encouraged or required to establish liaisons between their programs and other settings such as day care facilities, family day homes, group homes, and early childhood programs in the public schools?

-- If so, will this liaison include a system for assuring the child and family's smooth transition between and among agencies and programs?

PERSONNEL

Infants and their families require the services of professionals with wide variety of skills. If a team approach is used, working as part of a team is one of those skills. The team approach also requires state planners to examine carefully the varied roles and functions of team members as the planners develop guidelines for caseloads and staff-child ratios.

As state planners address the issue of licensure or certification, they should be aware that new services often require nontraditional staffing patterns and certification requirements. State planners should consider the development and enforcement of personnel standards that will ensure the highest quality of services to children and families. And, the should examine the issue of how new standards will affect personnel already working in infant programs. To ensure that competent service providers are not precluded from continuing their work because of new requirements, state planners may consider competency-based requirements to supplement or replace more traditional certification approaches.

Systems for preservice and in-service training are needed to develop or to retrain a corps of qualified personnel and to allow personnel to keep abreast of a rapidly changing field. And, liaison with institutions of higher education keeps colleges and universities aware of early intervention personnel training needs, including the need to keep pace with technological advances. As the benefits of interdisciplinary and transdisciplinary service models become widely acknowledged,

typical personnel preparation programs, which provide training in single disciplines, may need to expand to include training across disciplines.

Questions for Consideration: Staffing Patterns/Certification and Licensing

- o Will programs be required or encouraged to include staff from several disciplines, such as education, allied health, and social services?
  - -- If so, will the state take a position on the expected mode of team functioning, i.e., multidisciplinary, interdisciplinary, or transdisciplinary?

- o Will certification or licensing requirements be established for early intervention program personnel?
  - -- If so, will the state consider a competency-based certification procedure which examines experience in providing direct service to infants and families as an alternative to or substitute for other certification requirements?
  - -- Will college and university programs in the state be encouraged to offer courses and programs which lead to early intervention certification?
  - -- Will early intervention certification programs be encouraged to include coursework in cross-cultural education?

Questions for Consideration: Preservice and In-service Training

- o Will the state provide funding for preservice, in-service, and professional development training for staff?

- o Will specific preservice and ongoing or periodic in-service training be required for early intervention program personnel?
  - -- If so, how will these preservice and in-service training needs be determined?
  - -- Will the training needs of administrators and support staff be considered as well as the training needs of direct service providers?
  - -- Will multicultural sensitivity training be encouraged or made available to early intervention program personnel?

-- Will the state provide for the inclusion of information on technological development in in-service and preservice staff development training?

o Will programs be encouraged to contact federally funded projects located in the state and to use these projects as resources for staff training and development?

MONITORING AND EVALUATION

Monitoring and evaluation are related issues in assuring the highest quality of services to very young children with special needs and their families. Monitoring has two major and equally important purposes. First, monitoring assures that early intervention programs operate in accordance with the administrative and programmatic standards developed by the state. Second, thoughtfully developed and carefully implemented monitoring procedures can be used to assure that services provided by early intervention programs are of high quality.

Monitoring practices and instruments should reflect the objectives set by individual programs. The monitoring agency and the programs they monitor must share a clear understanding of the steps to be taken in the event that monitoring discloses noncompliance with standards or other quality issues. Incentives for program improvement and opportunities for technical assistance can help make the most of the potential for programs to view monitoring positively.

Evaluation is another tool for assuring the quality of services provided by early intervention programs. Program improvement should be the ultimate purpose of any program evaluation. State planners may consider developing a policy that requires programs to conduct program evaluation with some predetermined frequency. A complete program evaluation should measure and document child growth and development, family and child changes, and staff gains in knowledge and ability. Program evaluation also should provide an opportunity for parents to evaluate program services and their satisfaction with the program.

Programmatic goals and objectives for individual programs should be the standard against which program improvements and other changes are measured. That is, program evaluation must go beyond quantitative assessment of child gains to consider the quality of all aspects of the early intervention program.

Questions for Consideration: Monitoring

- o Who will be responsible for planning and implementing the monitoring system?
  - -- How will those responsible for program monitoring assure that interagency collaboration is a part of the monitoring system from its inception?

- o Will the current monitoring policies and procedures for the multiple agencies which are involved in early intervention be examined prior to the development of the monitoring system?
  - -- Will current standards and requirements then be coordinated so that they are consistent across agencies?

- o What will be the consequences for programs that are not in compliance with or do not meet the standards of the monitoring agency?
  - -- What procedures will be established to help these programs move toward compliance?
  - -- Will consultants and other technical assistance be provided?

- o Will the monitoring system examine quality issues of service delivery as well as compliance with regulations?
  - -- If so, how will exemplary programs be identified, recognized, and rewarded?

Questions for Consideration: Evaluation

- o Will programs be required to collect evidence of child, family, staff, and program evaluation?
  - -- Will programs be encouraged or required to submit this data to the state? If so, how will the data be analyzed and used by the state?
  - -- Will programs be encouraged or required to ask parents to evaluate program service and their satisfaction with the program?

- o Will programs be provided with funds for or technical assistance in evaluation planning, implementation, and reporting?

o Will the state conduct a statewide research effort as part of the state plan for early intervention?

-- If so, what information will programs be required to submit to help the state accomplish its research goals?

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